HALL C – DEMENTIA CARE

C.1  ReThink Respite: An innovative community intervention for carers of people with dementia aiming to improve knowledge about, attitudes towards, and use of respite
Presenter: Dr Elizabeth Cridland, Research Fellow, Australian Health Services Research Institute, University of Wollongong, Australia
Authors: Dr Lyn Phillipson (University of Wollongong), Dr Elizabeth Cridland, Dr Keryn Johnson, Dr Danika Hall

Despite the established benefits of respite, many carers of people with dementia are reluctant to use or are unaware of respite services or strategies. The ReThink Respite project was developed in the Illawarra-Shoalhaven region to address the barriers to respite use by implementing a multifaceted community intervention aiming to improve carers’ knowledge about, attitudes toward, and uptake of, respite services.

The innovative intervention involved the development and dissemination of various informational and navigational resources for carers, local service providers and health professionals. Project resources included a customised website, service directory, respite decision guide and checklists, and videos depicting local carers’ experiences of using respite services and strategies. All project resources were developed in consultation with key stakeholder groups and focused on respite benefits, education about the types of services and strategies to choose appropriate local respite services. Resources were distributed through the project website and over 20 community presentations.

Individualised support for carers and people with dementia was offered via ReThink Respite Coaching, a goal orientated program developed specifically for the project and delivered by health professionals in the participants’ homes. The coaching program included information and activities about day centre respite, in-home and flexible respite, counselling and support groups, residential respite, emergency respite, informal respite, and various respite strategies. Program activities encouraged participants to consider how their personal strengths and values may assist their organisation and use of respite.

The ReThink Respite intervention is being evaluated using a logic model incorporating a pre and post intervention survey of carers. Preliminary findings indicate the importance of better respite information pathways for people living with dementia and their carers, as well as the need for service providers to develop services that meet the diverse needs of this subgroup.
The community intervention has now expanded to include a national website and online program for carers of people with dementia called ReThink Respite Online. The innovative online delivery aims to increase access to the program and investigate the feasibility of online interventions for carers of people with dementia.

C.2 Filial motivation and staying power in the caregiver role when parents with dementia live at home
Presenter: Heidi Dombestein, PhD candidate, University of Stavanger, Norway
Authors: Heidi Dombestein and supervisors: Kristin Humerfelt (Associate Professor, PhD in Social Work, University of Stavanger, Norway) and Anne Norheim (Professor in Nursing Science, University of Stavanger, Norway)

Background: Like many countries, Norway has a substantial ageing population. The number of persons affected by dementia are anticipated to rise, and this will lead to great challenges for the health and welfare system. Persons with dementia make a growing demand on care, and family caregivers are often the most important supports when persons with dementia live at home. Research shows that caring for this patient group has been perceived as a stressful process. However, less attention has been given to caregivers’ motivation and staying power.

Aim: The aim of the study is to highlight the filial motivation and staying power in the caregiver role. By exploring these phenomena, we hope to contribute to the development of better ways of supporting caregivers and bring about improved outcomes for caregivers as well as persons with dementia. The research question asked is: How do adult offspring perceive motivation and staying power in their caregiver roles when their parents with dementia lived in their own homes?

Methods: The study adopted a qualitative approach whose data collection consisted of 20 individual interviews. The informants were grown up daughters (11) and sons (9) who were caregivers to parents with dementia who had until recently lived in their own homes. A semi-structured interview guide was applied, and the interviews were carried out retrospectively. The material transcribed from the datasets were analysed through systematic text condensation.

Result: The preliminary results of the study identify both internal and external motives for taking on and staying in the caregiver role. The filial understanding of the phenomena of stamina has been highlighted, and many factors that contribute to staying power in the caregiver role have been pointed out. An example is the crucial importance of acknowledgement and appreciation of caregivers’ effort not only by the persons with dementia, but also by the professionals in health and social services. The study will conclude in September 2017.

C.3 Strategies for relatives (START) online
Presenter: Associate Professor Briony Dow, Director, National Ageing Research Institute, Melbourne Australia
Authors: Dr Samantha Loi (University of Melbourne, Australia), Professor Colleen Doyle (Australian Catholic University, Melbourne, Australia), Joanne Tropea (Melbourne EpiCentre, Australia), Associate Professor Christina Bryant (University of Melbourne), Mark Tacey (Melbourne EpiCentre, Australia), Dr
Anita Panayiotou (National Ageing Research Institute), Ellen Gaffy (National Ageing Research Institute) and Hannah Capon (National Ageing Research Institute)

Australian carers of people living with dementia experience depression and anxiety at higher rates than any other group in our community. Programs are needed to assist carers to manage their role, particularly to understand and better manage the behavioural and psychological symptoms of dementia. These programs should be accessible to carers living in rural and remote areas, as in Australia it is not always possible to provide face to face interventions because of geographical distance.

The Strategies for Relatives (START) program was effective in reducing anxiety and depression amongst carers in the UK. START consists of eight sessions delivered face to face in a one-to-one format. It includes relaxation exercises and psycho-educational support to help carers better understand and manage behaviour as well as information on the service system. This study proposes to use video conferencing to investigate the practicability of individualised carer support delivered online based on the efficacious START model.

The project will first adapt the UK START program so it is applicable to Australian carers of people living with dementia, and then pilot a video conference version of the program. Video conferencing will enable close replication of the START approach including real-time delivery of the START program, as well as provide access for carers living in rural areas. The main aim of the pilot is to test the feasibility, acceptability and effectiveness of the on-line START program. A secondary aim is to evaluate the feasibility of rolling out such a program within the Australian health and aged care service system.

Thirty-five adult carers of people living with dementia will be recruited from both rural and urban areas of Victoria. Depression, anxiety, carer burden and quality of life measures will be completed at baseline and following the eight-week START program. In accord with the findings from the UK START program, we are expecting that participation in START will show a reduction in levels of depression and anxiety for Australian carers. We also anticipate that carers in this study will find a real time video-conferencing mode of delivery of the START program acceptable and feasible.

**HALL A – LIFE AFTER CARING**

**A.1 Post-caregiving: Family carers’ experiences of role and identity transition on cessation of the caring role – implications for policy and practice**

Presenter: Liam O’Sullivan, Executive Director, Care Alliance Ireland

Authors: Dr Carol Kelleher (University College Cork), Liam O’Sullivan, Sally-Ann Back (West Cork Carers Support Group, Ireland) and Paul O’Mahoney (Family Carers Ireland, Ireland)
This presentation on the POSTCARE project highlights how successful partnerships between carers, care recipients, researchers, carer associations and policy makers can improve the lives of carers and their care recipients at a regional and national level in Ireland.

The central aim of the Irish National Carers’ Strategy (2012) is to recognise the value and contribution of carers to civic society, and to support and empower them to participate as fully as possible in economic and social life. Post-caregiving involves significant challenges for former carers including: return-to-work or education; economic and financial challenges; rebuilding social networks; changed family relationships; dealing with complicated grief; and identity rebuilding. However, the far-reaching and complex economic, social and psychological needs of former carers remain misunderstood and unmet.

POSTCARE is a collaboration between University College Cork, West Cork Carers Support Group, Family Carers Ireland and Care Alliance Ireland funded under the Irish Research Council New Foundations programme. Its aim was to develop evidence-based supports and policy to support former carers post-caregiving by providing a nuanced knowledge of family carers’ post caregiving experiences of loss, role and identity transition on cessation of the caring role, and thus specifically respond to aim of the National Carers’ Strategy, i.e ‘to review existing transition arrangements for carers at the end of their caring role’.

Using a participatory action research approach, POSTCARE prioritised responsive information exchange with those most impacted by the research, namely former carers, and responded to the issues, challenges and concerns facing former carers via a series of participant led workshop and supports. Through dialogue with 23 former carers (13 women and 10 men) and three regional and national Carer Associations, the project outputs incorporated guidelines, an action plan and the co-development of peer-supports to change and influence policy and practice.

Overall, POSTCARE has informed national policy and the delivery of carer supports in Ireland and internationally, thus empirically and practically addressing carer needs as prioritised by the National Carers’ Strategy and fostered continued engagement with partner NGO’s on a longer-term basis.

A.2 Relatives’ experiences related to a close family member’s stay in an intensive care unit
Presenter: Assistant Professor Gro Frivold, University of Agder, Norway
Authors: Assistant Professor Frivold (MNSc, CCN), Professor Bjørg Dale (PhD, RN, University of Agder) and Professor Åshild Slettebø (PhD, RN, University of Agder)

Relatives of intensive care patients often suffer from long lasting consequences like anxiety and depression after returning home. Intensive care patients are often in need of support in their recovery from critical illness, and close relatives frequently act as informal caregivers. Some suffer from complicated grief after the loss of their loved ones. The aim of this study was to illuminate family members’ experiences of being a close relative after a stay in an intensive care unit (ICU).
A qualitative, phenomenological hermeneutical method was used to illuminate family members’ experiences during and after their stay in the ICU. Thirteen close relatives were interviewed from three months to one year after the discharge or death of the patient.

The family members experienced emotional reactions and changes, and memories from the ICU stay influenced their everyday life, after the return home. They experienced new roles and new responsibilities. They managed the changes and adapted to the situation by maintaining control and use their own personal strength. However, receiving help and support from others seemed to be important. Some of the relatives were also in need of professional support or follow up from the ICU staff.

This study’s recommendation for clinical practice is that health professionals should have an increased focus on the changes and challenges that family members experience after an ICU stay. Quality of the relationship between the relatives and the ICU staff seemed to affect the family members’ ability to cope with the experiences in retrospect.

**A.3 Recovery from care: Former carers’ experiences and support needs**

Presenter: Dr Timothy Broady, Senior Research and Development Officer, Carers NSW, Australia
Authors: Dr Timothy Broady and Tom Hinton (Policy and Development Officer, Carers NSW)

Internationally, former carers represent a large gap in research and policy. While a great deal of evidence exists regarding the needs and experiences of carers at different stages of their caring role, comparatively little attention has been paid to carers’ needs and experiences when their caring role ceases, whether through the death of the person they care for or the carer’s choice to no longer provide care.

The little evidence that does exist is generally focused on a short timeframe beyond bereavement. This presentation aims to extend current knowledge regarding the experiences of former carers, and consider new opportunities to support them as they transition from a life characterised by the care and support of others into a new phase of life without the same level of demands or expectations. A theoretical approach to understanding carers’ self-perceptions of their own identity will be used to frame recent empirical findings.

Results from a large scale survey of carers (including former carers) across the state of New South Wales, Australia, will be discussed, particularly in light of the vast body of existing research that indicates caring significantly effects wellbeing. From this perspective, this presentation will explore the extent to which it is possible for carers to recover from the adverse impacts of their caring roles once they have ceased. Through this discussion, particular life domains which require the most intervention and support will be identified, with implications for carer support and policy across international contexts.

**HALL B – INTERNATIONAL CARING**
B.1 Family caregiver support: A new way to meet health services’ challenges and demands
Presenter: Kari Kjønsberg, Special adviser, Centre for Addiction Issues at Sykehuset Innlandet Hospital Trust, Norway
Authors: Special Adviser Kari Kjønsberg and Special Adviser Anne Christine Moberg (Sykehuset Innlandet Hospital Trust, Norway)

Expenses in health care are increasing in the western world due to needs of new groups of patients and an increasing amount of elderly people. Innovative solutions are therefore needed. The potential for collaboration between family caregivers and service providers is huge and may meet this demand. We have developed a program that facilitates the exchange of ideas and practices. Both family caregiver organizations and health services collaborated in the development of our program as well as they participate.

The main aim of our program is to establish 1) robust systems for collaboration between caregivers and services, and 2) support for family members that meet their unique needs. The program has three central components.

1. Eight seminars for service providers to strengthen competence. Additional guidance is provided through local groups to help providers transform knowledge into practice.
2. Three sessions for program managers outlining their role and responsibility for development and implementation. Tools for supporting leaders in this task are introduced.
3. Implementation groups that last over a 12 months period, where service providers and managers can share and develop new practices and organize a process that will lead to a local plan for action.

Results and experiences will be evaluated after our pilot program period ends (May 2017). Experiences of the program process and tentative results from evaluation will focus on our methods in the three central program components, to judge their relevance for future development in health care practice and will rely on two perspectives: 1) outcome for practice, mainly seen as procedures for regulating cooperation with and support for caregivers, and 2) to what degree involved leaders and service providers find the methods useful.

The objective of this presentation is to show what is needed to develop a better policy for supporting family caregivers. We will introduce some possibilities for systems and partnerships that will offer greater support, and will address some of the challenges that may be encountered.

B.2 Carers’ unforeseen uncertainty in ‘Integrated Community Care System’ in Japan: Findings from voices of carers
Presenter: Professor Mai Yamaguchi, Japan Lutheran College, Mitaka
Authors: Professor Mai Yamaguchi, Associate Professor Akemi Matsuzawa (PhD, Ibaraki Cristian University, Japan), Professor Eiko Horikoshi (Japan Women’s University, Bunkyo), Professor Ikushi Yamaguchi (PhD, Meiji University, Chiyoda, Japan), Professor Machiko Ohara (PhD, Japan College of Social Work, Kiyose) and, Professor Hiromi Nakamura (PhD, Saitama Prefectural University, Koshigaya, Japan)
It is crucial agenda to create a sustainable caring society for Japanese super-aging society. Japanese government takes the strong initiative to create ‘Integrated Community Care System’. However, the recent policy reforms, such as the 2014 Long Term Care Insurance (LTCI) Reform, the 2015 National Dementia Strategy, the 2016 Child Care and Family Care Leave Act Reform and the policies to prevent giving up jobs due to caring roles, seem to move toward the direction that the scope of formal care is shrinking and the reliance on informal carers are increasing. We need to understand the difficult reality of carer’s daily life under such changing contexts.

The purposes of this presentation are to explore Japanese carer’s difficulties under the Integrated Community Care System and to discuss challenges to support various carers in Japan. Based on interviews with carers, we found that carers faced unforeseen uncertainty even under the Japanese integrated community care system.

Firstly, carers are concerned about unexpected a financial burden and poor quality of care at care facilities provided by private sectors outside LTCI services. Due to the limited availability of formal care services, it is getting difficult to find appropriate care facilities under LTCI program. Secondly, carers for those with dementia dwelling in the community face various unforeseen difficulties to manage daily life. Thirdly, working carers always face unpredictable concerns since balancing work with care responsibility is very difficult under Japanese business contexts. For those who have given up job, it is difficult to find new jobs after caring roles were over.

Understanding these voices of carers, we need to support carers who struggle to overcome unforeseen uncertainty. However in Japan, supports for carers are fragmented, and there is no effective integrated support for carers. Our biggest challenge is to raise public awareness that all carers including carers for persons with disability should be recognized not as cheap resources but as citizens. Another challenge is mainstreaming carer issues in policy debate. Strategic networking and collaboration among carers’ organizations, carers and ex-carers is needed.

B.3 Are we truly helping care-givers? Comparing the efficacy among care-giver service center types
Presenter and author: Professor Chen-fen Yvonne, Chinese Culture University, Taipei, Taiwan

In ageing societies, policymakers aim for more contact between informal and formal care-givers as it may enhance the quality of care, and also reduce the burden on family care-givers. Taiwan’s new administration will support the establishment of 16 new care-giver service centers in 2017, in addition to the 10 supported centers in 2016.

So far, the linkage between informal and formal care-givers is generally studied from a one-sided or a single dyadic perspective, without taking into consideration that care networks of community-dwelling older adults often consist of multiple informal and formal care-givers and organizations. This study will first examine why organizations want to become care-giver centers.
Next, I will examine their target populations, characteristics and service programs in order to evaluate the organization’s position and strategies. I will also look at the relationship between all care as it relates to organizations in a care network. I expect this research will provide an abundance of crucial information for policy-making for care-giver service centers in Taiwan as well as to illuminate whether these service centers truly support care-givers by reducing their care burden and help to better connect them with formal and informal care providers in their networks.

**ROOM H1 – EMERGING TECHNOLOGIES**

**H.1 Driverless vehicles and carers: Will it have an impact?**
Panel Discussion
- Rita Excell- Australian Driverless Vehicle Initiative
- Steve Harrison- Adelaide City Council
- Dr David Panter- ECH (Aged Care Provider) & SA Council of Social Service
- Grace Vassallo- Carer
- Simon Pearce – high-tech startup, EasyMile

Introducing the theme of how technology will transform our lives and how transport is a key part of this. Each panellist will provide a 10-minute summary their organisation/background, explaining why this is important to them and the role they see technology playing.

**H.1.2 Before the Fall - Using technology to capture non-expert observations to pre-empt acute scenarios via private online networks of family and friends**
Presenters and authors: Stewart McCure and Owen Batt, Familyze

A highly interactive, discussion-based workshop using the use case of ‘Falls’ to explore the difficulties presented by asymmetrical information networks around an older person living independently at home.

- Who in the informal network knows what? (the offhand remark about ‘a slip’, an abrasion or bruise)
- Who should know? (carers, selected family members, other experts)
- What information can be made available to HCPs and other experts in a timely manner to allow for pre-emptive interventions? (review of medication, installation of safety apparatus, IoT)
- How can technology improve the capture, retention and transmission of this informal, non-expert information in a time-poor world?
With the near-universal goal of keeping our ageing population living independently at home we need to make timely decisions with as much information as is available. Familyize uses social technology to assist in capturing a broad base of information in the face of increasing time pressures on carers.

ROOM H2 – PALLIATIVE CARE
Sponsored by the Australian Government Department of Health

H2.1 My End of Life Care campaign – Australian Government Department of Health

The Department of Health is working on a range of materials to highlight the importance of having a conversation around palliative and end of life care. Further information about My End of Life Care communications resources can be found on an information card in your conference packs.

It is important to start talking early about end of life care as this allows control over choices and can reduce the burden on family and loved ones. To help start the conversation, we present to you a video titled, *Talking About What Matters*.

H2.2 Challenges and best practice of support and wellbeing of informal carers
Presenter and author: Angela Smith, Development & Support Officer, Carers Tasmania, Australia

Internationally and in Australia there is growing emphasis on consumer directed care in at home aged care services and giving patients the choice in their own health care including the choice of dying at home. Informal family care givers quite often have little or no medical training yet are crucial to the overall support team and the medical care for palliative patients at home.

I have substantial experience within the community sector in Tasmania, primarily in services supporting the informal carer. In 2016, I became the primary carer of my mother-in-law who was diagnosed as palliative, and wished to die at home. Initially state palliative health services provided the family with a folder of information to be perused at the family’s leisure which included a carer brochure. In 2012, Tasmania was also given significant funding for a Tasmanian Health Assistance Package to ease pressures and equipment on Tasmania’s health system to meet future challenges for palliative support.

Since ceasing the caring role I have reflected on this caring journey and how the aged care programs and service providers supported the family. This journey gave me the lived experience of the high burden of care faced by the family care giver and the support provided by community services. In my experience most carer assessments undertaken were name gathering exercises for the recipient file only. There is no referral pathway offered to the carer. This led me to research peer reviewed journals, numerous studies on the carer burden, assessment tools and discussion papers.
Improved transfers of care between health and aged care sector are vital and case studies will be presented to show this. This combination of my lived experience and professional role has identified the need for a comprehensive carer health and wellbeing component in palliative care or high burden on the family, with clear referral pathways to assist the home care provider and health services.

**H2.3 The impact of a multi-sensory room on the wellbeing of those utilizing hospice care**

Presenter: Michelle McClure, Manager and clinical nurse, Albany Community Hospice and Efterpi Soropos, HUMAN ROOMS™ designer, Albany Community Hospice, Australia

Authors: Michelle McClure, Efterpi Soropos and Associate Professor Kirsten Auret (Rural Clinical School Of Western Australia, University of Western Australia, Albany)

Albany Community Hospice (ACH) is a new eight-bed rural inpatient palliative care unit, which offers a home-like setting for individuals who have end stage illnesses that require holistic care for control of symptoms or who are unable or do not wish to remain at home to die.

From the earliest design stages for the new ACH building, there has been a vision to include an innovative indoor and outdoor space that could become a Human Room™. The Human Room, developed by Efterpi Soropos, is a purposely designed, peaceful and harmonious room that provides a self-directed immersive, experiential space that can assist participants to reduce stress, and induce relaxation and meditation. The content (video, sound and colour lighting sequences) was created to suit the needs of patients and their carers and is influenced by research, place space, preference, embodied memories, biophilia and Efterpi’s 25 years experience of designing performing arts environments. The content is delivered by a system that allows participants to have control and engage with a variety of options. The interior architecture of the room is designed to absorb and reflect the sensory content and create an atmosphere that enables participants to reconnect with themselves and the environment presented in the room.

The Human Room successfully operating in ACH was designed in partnership with the local community, utilizing the knowledge and talents of local artists, artisans, architects, musicians, video makers, academics, clinicians, businesses, environmentalists and volunteers from the Great Southern Region of Western Australia.

This presentation by the senior nurse manager from ACH and the Human Room designer will showcase the design and implementation of the space and share case stories describing its impact on patients, carers and staff wellbeing. The objective is to encourage other organisations to consider the use of multi-sensory and experiential places in their facilities.

[55 minutes]
**ROOM H3 – YOUNG CARERS**

**H3.1 Creating opportunities with young carers aged 5 to 25: Empowering them to reach their potential**

Presenter: Nadia Yacoubi, Young Carer Senior Coordinator, Carer Support and Respite Centre Inc and a team member
Authors: Carol Sparrow (Carer Support & Respite Centre Inc, Adelaide, Australia) and Nadia Yacoubi

Carer Support’s Adelaide-based young carer program, Raw Energy, has been developed over the last two decades. The program currently supports 157 young people aged 5 to 25 years. Our practice is based on feedback and on principles and best practice research by Saul Becker and other researchers, such as Bettina Cass.

We offer holistic support and child and youth focussed activity including: 1:1 support, advocacy, peer activities, social media support groups, camps and retreats, school based support, referrals to other services, whole of family support, community engagement, partnerships with other agencies to benefit young carers and their families, mentoring, tutoring and role model behaviour. Group based activity is according to age so we have four cohorts, the 5 to 9 years; 10 to 13s; 14 to 17s and 18 to 25s.

We assist individual young carers to achieve personal recognition through applications for bursaries, for grants and for awards such as the Young Achiever Awards. We raise community awareness and generate donations through a range of channels. We collaborate with our young carers to develop the program and determine what works best for each age group and for each individual.

A particular element of the program that we will share is our ‘Inside Out’ three day retreat for 14 to 17 year olds. The title refers to ‘our outside world’: trying new experiences, exploring limits, taking risks, developing strategies, teamwork, trusting their instincts and how this makes them feel. Past activities have included paintball, surfing, mountain biking, bushwalking, self defence and yoga. ‘Our inside world’ is an exploration of thoughts and feelings through gender based workshops and peer discussions, on topics such as mindfulness, life balance, playfulness and stress reduction, life planning, nutrition, wellbeing and building emotional intelligence. Activities to address these topics include small group discussion, art therapy, creating journal logs, ‘Wheel of Life’ domain assessment tools, mental health, fitness and nutrition workshops. We also provide take home resources. Conference delegates will gain an understanding of what works for young carers and of an effective service delivery model.

**H3.2 The Ignatian Model: A Saint Ignatius’ College community partnership seeking to better support students facing adversity**

Presenters: Elizabeth Robinson, Parent Volunteer and Robert Passaniti, Deputy Head Pastoral Care and Administration, Senior College, Saint Ignatius’ College, Adelaide, Australia
Authors: Elizabeth Robinson, Dr Manya Angley (Saint Ignatius' College), Robert Passaniti, Andrew Dodson (Saint Ignatius' College) and Peter Coffey (Saint Ignatius' College)
St Ignatius’ College, Adelaide, has a comprehensive and student-centered pastoral care framework that is continually reviewed and enhanced. However, given the unique nature of ‘young caring’, two College parents partnered with school leadership to explore how to better understand and support young carers and other students facing a broad range of adversity, including illness and loss of a family member.

The objectives are to determine:

- How can a school better support its students facing adversity?
- How can a school better engage students/caregivers in letting the school know how they can help during times of adversity?

A literature review of published and grey literature informed preparation of a briefing document. A Student Engagement Reference Group (SERG) was established, comprising senior students who had experienced ‘adversity’ during their schooling. A focus group with the SERG (n=8) and semi-structured interviews with staff members (n=20) were conducted to explore participants’ information needs and experiences as, or with, students facing adversity. Qualitative data was analysed thematically.

Qualitative research revealed challenges faced by students facing adversity included managing workload; the unpredictability of the course of the care recipient’s condition/their own illness; disruption and distraction which can impact on academic performance; sleep disturbance and resulting tiredness, difficulty concentrating and stress; isolation; a perception that the care recipient’s needs are always first priority in family; inability to participate in key school activities; and having to ‘retell’ their scenario repeatedly.

Future beneficial initiatives identified by the students were improved ‘case finding’; a student hub as somewhere to talk, share and have time out; a mentor program; a camp (with mentors); and an IT platform with signposting, contact details and forms to assist students and caregivers in navigating support. Findings from staff interviews were generally congruent with those from the SERG focus group. Staff perceived that students facing adversity needed empathy, respect and understanding. Strategies identified by staff to assist students included an individualised approach and guidance to make the right choices through empowerment; and accepting that support is a functional necessity of life. Opportunities to build rapport between students and staff was viewed as key to students seeking help.

H3.3 Exploring identity and negotiating life paths: The experiences of young adult carers in the United Kingdom and the United States
Presenter and author: Feylyn Lewis, Doctoral Researcher, University of Birmingham, United Kingdom

Young adult carers are those individuals aged 18 to 25 years who provide unpaid care, support and assistance to a family member with a health condition, such as a physical or sensory impairment, mental illness, and/or other condition that requires support (e.g. substance misuse or chronic health problems). In the United Kingdom, there is an emerging awareness of the experiences of young adult carers, particularly of those in education and employment. Conversely, the lives of young adult carers in the United States remain largely hidden from the view of researchers, policy-makers and social care advocates.
Young adult carers play an important role in supporting their families, while also serving as the safety net of the indisputably strained social care system in both countries.

For young people with caregiving responsibilities, young adulthood may represent a time of instability, change and decision-making, particularly for relationships, careers, education, and financial independence. From a psychosocial perspective, these life domains are often thought to have an important influence on the development of identities. However, we know little about the deeper, internal effects of providing care during young adulthood and the potential impact that caring responsibilities may have upon the development of identities and the negotiation of life paths during young adulthood.

This presentation will provide attendees with a deeper understanding of the ways young adult carers may explore their conceptualization of identity during caregiving, while also considering their navigation of multiple life domains as they transition into adulthood. Enriched by the presenter’s own experience as a young adult carer, this presentation draws upon the knowledge gained through 55 qualitative semi-structured interviews with young adult carers in the United Kingdom and United States; conducted as a part of the presenter’s doctoral research project. The presenter will address the unique challenges facing young adult carers in their respective countries as they explore the various facets of their identity. Delegates can also expect to receive recommendations for best practice in supporting young adult carers in their consideration of life paths and their transition to adulthood.

**ROOM H4 – PARTNERSHIPS**

**H4.1 Faith-based care navigation for carers of persons with advanced illness**

**Presenter:** Dr. Janice Bell, University Of California, Davis, Sacramento, United States  
**Authors:** Dr. Janice Bell, Rev Cynthia Carter-Perrilliat (Allen Temple Baptist Church, Oakland, USA), Valerie Steinmetz (Public Health Institute, Oakland, USA), Dr Jill Joseph (University of California, Davis, Sacramento, USA)

The Alameda County Care Alliance Advanced Illness Care Program (AICP) is a novel person-centered, faith-based, lay care navigation (CN) intervention in California, USA, designed to meet the needs of persons with advanced illness (AI) and their carers in alignment with their spiritual values and cultural preferences. The AICP deploys AI CNs based in eight predominantly African American Baptist churches, who form trusting relationships with participants and help to identify resources—within family caregiving networks, congregations, and community—that can be deployed to support participants. Originally developed by and for community members in collaboration with academic, public health, health system and policy partners, the AICP is open to all, regardless of race/ethnicity or faith. This presentation describes the intervention, its implementation and early evaluation with a focus on the perspectives of carers.
Evaluation data are collected from active and bereaved carers through telephone surveys, in-person interviews and data abstracted from CN visit summaries. The analysis employs both qualitative and quantitative methods.

To date, the AICP has served over 250 carers (one-third are not church members, instead referred by local clinical sites)—predominantly women (87%), caring for family members (79%) and many providing 24/7 care (40%). Most report moderate (44%) or severe (25%) caregiving burden and half reported their own health was good/fair/poor (compared to excellent or very good). Top carer needs included respite care, prayer, assistance to meet their loved ones’ dietary needs, and support for advanced care planning. Through AICP participation, carers reported many of their needs were addressed and that they developed more assertive relationships with health care providers as well as greater ability to articulate their needs. Program satisfaction scores were high, with all reporting they would refer friends in similar circumstances for participation.

The AICP harnesses many strengths of faith-based communities—including shared cultural beliefs and values, trust, social networks, and tangible/intangible resources—to meet the needs of carers of persons with advanced illness. The AICP has significant potential for scale-up and dissemination to other countries, racial/ethnic groups, and faith-based settings (e.g., churches, synagogues, mosques).

H4.2 The Carers Worldwide approach: Working with local partners to transform the lives of unpaid family carers in low and middle income countries
Presenter and author: Anil Patil, Founder and Executive Director, Carers Worldwide

Carers in low and middle income countries (LMIC) receive no government recognition. There are no organisations exclusively addressing the needs of carers, most of whom are family members (84% female) and unpaid. Working across India and Nepal, Carers Worldwide seeks to fill that gap, establish carer-specific services at grassroots level and advocate at policy level to secure long term change for carers.

This presentation will show how a holistic, replicable model of working in partnership with local organisations who are tackling the issues facing those with disability or mental ill-health, the elderly or chronically sick, and who are already well respected in their local communities, can transform the lives of carers who were previously unrecognised and invisible.

Carers Worldwide consults with local carers and families to understand the issues that impact most significantly on their quality of life. Our recent surveys in Nepal and India have found 84% of carers experience physical health issues and 86% report significant effects on their mental health. Families commonly experience loss of two incomes – cared-for and carer. 92% report significant financial burden, often exacerbated by costs related to the affected person’s disability or health needs. 64% of carers are of the most productive age for earning. More than 75% of carers with whom we work are living below the poverty line before we meet them.
By developing programmes that most effectively meet local need, Carers Worldwide develops the skills and builds the capacity of local partner staff and stakeholders in health, education and social care, enabling them to establish carer-specific services that will relieve the health, social and economic impacts of caring. Alongside this, we empower carers to engage with service providers and policy makers, thus creating a joint legacy of skilled local staff and informed carers who together are able to improve the lives of carers and cared-for.

The objective of the presentation is for delegates to appreciate the scale of the issues facing carers in LMIC (currently unmet) and understand how a low-cost, holistic approach, working in partnership with local organisations, stakeholders and carers can meet those needs in a sustainable way.

H4.3 Admission2Discharge Together – improving the hospital journey and health outcomes for people with intellectual disability and their carers

Presenters: Janice Oliver, Manager Carer Program, South Eastern Sydney Local Health District, Sydney, Australia and Lif O’Connor, Clinical Nurse Consultant, Developmental Assessment Service and Metro-regional Intellectual Disability network, South Eastern Sydney Local Health District

The Admission2Discharge Together Project (A2D Together) is a collaborative partnership between South Eastern Sydney Local Health District and Family and Community Services. The aim of the project is to improve the hospital journey for people with an intellectual disability, their carers/families and disability support workers.

The literature shows that people with an intellectual disability have poorer health outcomes than the general population, and their health issues are often undiagnosed, misdiagnosed or poorly managed. This project was developed to support people with an intellectual disability during hospital admissions and assist health staff to provide person centred care, by providing current and relevant medical and personal information. The A2D Together Folder contains key information about the person including immediate risks, interests, likes and fears to help reduce anxiety, communication tips such as the sign used for toilet and what may trigger particular behaviours.

Face-to-face training has been provided to more than 550 health and disability staff across our Local Health District. The training has a human-rights base, focusing on person centred care, attitudes toward people with disability, ways to improve the integration of care and inclusion of carers.

A comprehensive evaluation has shown the benefits of the use of the A2D Together Folder for the person with a disability, their carer and family, disability support staff and health staff. Staff told us, they feel more confident caring for people with Intellectual Disability and their responses demonstrated a change in attitude.

The Future: an online toolkit is available for people with a disability, their carers, families and health and disability staff. It includes two short film clips demonstrating the use and value of the A2D Folder - one from a carer perspective and one which follows a person’s hospital journey. It also includes the tools to download, with information and instructions on how to use them.

15
CITY ROOM 1 – SYMPOSIUM – OLDER CARERS

CR.1 Caring in later life: Reflections on current challenges
Presenters: Professor Liz Lloyd, University of Bristol, UK; Professor Alisoun Milne, University of Kent, UK; Dr Mary Larkin, The Open University, UK; Jo Moriarty, King's College, University of London, UK

This symposium will focus on a group of carers, which is growing in number internationally but which until recently has received little policy, practice or research attention. Older people are frequently portrayed as the ‘recipients’ of care, when in fact they are also major providers of care.

The four papers in this symposium will discuss the distinctive profile of caring in later life, what the nature of late life caring is and suggest how support for older carers might be developed. A focus on caring in later life brings into sharp focus familiar questions, such as:

- How do we understand the identity of a ‘carer’ when relatives do not recognise the label or two people are co-caring?
- What happens to the carer when the person being cared for dies or is admitted to long term care?
- How we understand caring embedded in a lifelong relationship
- How do we respond to carers’ needs and what they say they want?

At later stages of the life course these questions generate different answers and require different policy, service and practice related responses.

The presenters are all researchers in British Universities and share a strong commitment to producing findings that are relevant and useful to carers and their representatives as well as to policy-makers and practitioners, whose job it is to develop support for carers.

CITY ROOM 2 – SYMPOSIUM – MENTAL HEALTH CARE

CR.2 A practical guide for working with carers of people with a mental illness
Presenters: Dr Sarah Pollock, Mind Australia; Janne McMahon, Chair and Executive Officer, Private Mental Health Consumer Carer Network (Australia) Limited, Adelaide, Australia, Professor Sharon Lawn, Flinders University, Adelaide, Australia, Christine Kaine, Senior Project Officer, Private Mental Health Consumer Carer Network (Australia) Limited and Patrick Hardwick, President, Mental Health Carers Australia and Helping Minds WA, Perth, Australia
In any given year, almost 2.5 million people care for a person with mental illness in Australia. A Practical Guide for Working with Carers of People With A Mental Illness is a hands on, standards based tool designed to help mental health services engage more effectively with family and carers, comply with legislative and accreditation obligations, and improve recovery for consumers and carers. The Guide, available as a free download, is founded on the UK Carers Trust model, the Triangle of Care. It is based on six partnership standards. The standards can be applied across all settings and incorporate age related, cultural and other needs. Each Partnership Standard is accompanied by an easy-to-use self-assessment tool, and practical examples and suggestions about how to implement each one.

This Guide recognises carers are a crucial component of any partnership approach to service delivery. It has been developed to assist staff across service settings in recognition and support of carers, to enable them to continue in their role as partners in recovery. The Guide aims to enhance the capacity of mental health providers to meet the increasing number of standards which guide mental health delivery. It assists in streamlining and supporting service providers to meet their obligations under the National Standards for Mental Health Services.

This symposium will provide:
  - an overview of the Guide, including underpinning research, partnership standards, self-assessment tools and action plans
  - practical resources developed to support service providers to effectively engage carers in mental health settings including an online repository/library for service providers
  - a review of demonstration projects undertaken in Australia to assess implementation of the Guide.

CITY ROOM 3 – SYMPOSIUM – COMBING WORK and CARE

CR.3 Innovations in supporting carers to combine work and care: International perspectives
Presenters: Professor Sue Yeandle, CIRCLE, University Of Sheffield, United Kingdom; Professor Janet Fast, RAPP, University of Alberta, Canada; Dr Myra Hamilton, SPRC, UNSW Australia; Mayuko Nakai, Ministry of Internal Affairs and Communications; Professor Michael Fine, Macquarie University, Australia

This symposium will include presentations from Australia, Canada and Japan, on innovations and policy changes introduced in the past 2-3 years with the aim (explicit or implicit) of enhancing support for carers who wish to combine work and care. Each will discuss specific innovation(s), exploring: challenges in implementing the innovation; outcomes for carers/those they care for; and policy responses to the innovation, as its potential, risks and opportunities have emerged.

The focus will be on three types of innovation:
  - innovations in technology; widely seen as offering innovative solutions to the challenges carers of older or disabled people face (especially as carers of a parent/spouse) in juggling complex or unpredictable work-care responsibilities
Innovations in care and disability policy, where programmes offering personalised or consumer-directed support often include an expectation that they will enhance employment rates.

Innovations in employment policy; where developments in law and employment practice offer the prospect of arrangements which can support working carers’ work performance, help them remain in the labour market, and reduce the pressures many experience when work and care ‘collide’.

CITY ROOM 4 – WORKSHOP – EQUIPMENT USE

CR.4 Creative use of equipment: Five opportunities to avoid manual handling
Presenters and authors: Aideen Gallagher, Occupational Therapist, Risk Managed, Croydon, Australia

In 2015, almost 2.7 million Australians were unpaid carers (11.6%) (ABS, 2015). They enable many of the 4.3 million people with a disability in Australia to remain in their own home. However, injuries amongst care givers are high and manual handling injuries account for 29% of all the workplace injuries (Workcover, 2012). In addition, care in the home offers challenges when physical spaces are not designed for the care tasks required.

Injuries occur with increased exposure to manual handling. Equipment solutions have proven to be an effective way of reducing this exposure to manual handling. Innovation is booming in the manual handling sector with new equipment options being created all the time. Many care givers never get the opportunity to discover how the clever use of some of the already known items of equipment can reduce manual handling.

Risk Management is the process we use to solve manual handling problems. After the risk has been identified and assessed, risk controls are put in place to solve it. Elimination is the most effective risk control measure in the avoidance of manual handling and therefore injury. This workshop will use the principle of elimination to show how the clever use of basic manual handling equipment can result in reduced exposure to manual handling.

By the end of this workshop delegates will know:

- How to identify if a client has the abilities for a standing transfer and equipment solutions that can assist with their transfers
- How to identify if a client has the abilities for a lying to sitting transfer and equipment solutions that can assist
- How to identify if you have the right hoist to transfer a non weight bearing client to avoid unnecessarily manual handling
- How to use various techniques and equipment to eliminate manual handling in rolling
- How to creatively move equipment in tight spaces